

Strategic Review of Palliative care - call for evidence

Terms of Reference

1. Introduction

Central London, Hammersmith & Fulham and West London Clinical Commissioning Groups have launched a strategic review of palliative care across the boroughs. The review will look to recommend a new commissioning model that delivers high quality care and services locally for patients, their families and carers.

Who is leading this?

The review is being led by an Independent Chair, Penny Hansford, supported by a Clinical Steering Group (CSG) which will review national strategy, policy and best practice alongside local context and the need to develop a sustainable clinical model.

Penny Hansford has had an extensive career in palliative care and has spent the last eighteen years as Director of Nursing at St Christopher's Hospice in South London. During this time she led or co-led many new innovations and changes in service models to fit with the changing demography of dying.

She recognises that to improve palliative and end of life care there needs to be a far greater level of integration and working together between health, social care, the voluntary and acute sectors and mental health services. Empowering informal carers and developing communities to care for people at the end of life must also be an important strand in our thinking.

The process

As part of the review the Independent Chair is launching a call for evidence. Patients, families, carers and local stakeholders, together with experts in the field are invited to submit written evidence to support the development of the Independent Chair recommendations.

The Independent Chair will use this evidence to develop a final report, with recommendations of the best model of care for palliative care services.

The outcome

The recommendations will be considered by the CCG's Governing bodies. The final report will be published alongside CCG commissioning intentions for palliative care services in spring 2019.

2. What is the scope of the review?

Definitions

Palliative care has been defined by NICE as 'the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of

psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families’.

A core component of palliative care is support at the end of life. NICE guidance defines the “end of life” stage as people with:

- advanced, progressive, incurable conditions;
- those who may die within 12 months; and
- those with life-threatening acute conditions.

End of life care covers any support and treatment for those nearing death.

Focus of the review

This review will consider issues around the end of life for all people, but is primarily focussed on the delivery of palliative care. This review covers day care, community care and bedded care as well as wider support services for families and carers.

Aims

There is a significant volume of national evidence on what good palliative care looks like. What is less clear is how our existing system needs to adapt to reflect local need and changing patient preferences.

The Independent Chair will be looking to put forward options on how the local system can remain sustainable while being able to adapt to ensure that all patients continue to have the ability to receive care in their preferred place at the right time.

The Independent Chair will need to ensure that the options put forward enable the local system to:

- respond to the voices of people with palliative care needs and their families
- improve support to primary care to deliver high quality end of life care for their patients.
- improve the quality of care delivered in all settings and works in an integrated way to ensure this.
- grow the capability of informal carers in communities
- ensure strong strategic connections across and between all professionals who provider palliative care to ensure sustainable and seamless care is in place for patients, their families and carers.

The review will consider the significant body of work completed at a national level on palliative care, including work undertaken by the following bodies:

- Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2010
- National Palliative and End of Life Care Partnership
- Commissioning Person Centred End of Life Care
- NHS England Actions for End of Life Care
- NICE quality standard 13
- National End of Life Care Intelligence Network
- Emerging themes and deliverables

The review will also consider local context and needs including the 2016 Joint Strategic Needs Assessment for end of life care in the boroughs of Hammersmith & Fulham, Kensington & Chelsea and Westminster.

This put forward five key recommendations for the health and care system to:

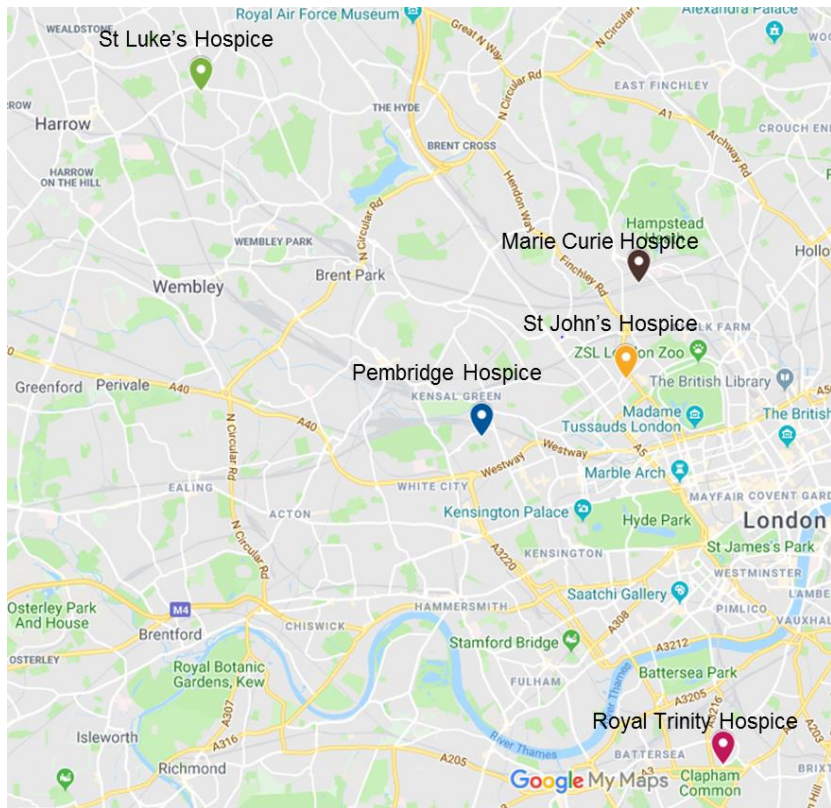
- maximise choice, comfort and control through high quality effective care planning and coordination;
- promote end of life care as 'everybody's business' and develop communities which can help support people;
- identify clear strategic leadership for end of life care across both social care, health and the independent sector;
- develop a coordinated education and training programme for practitioners, the person dying, carers and for family and friends (if they wish); and
- everyone should have easy access to evidence and information.

The review will also consider current system performance in relation to national strategic outcomes and provide snapshot analysis of each service offer (in-patient and community) - (CLCH, St. Luke's Hospices, St. John's, Marie Curie and Royal Trinity). Alongside this, the strategic review will also provide analysis of changing demands on palliative care services.

Most importantly, the review will consider what matters to people receiving palliative care, and their families and carers including views of informal carer's experience of services (VOICES).

3. Local Specialist Palliative Care Services

The three CCGs of Central, West and Hammersmith & Fulham commission three hospices: Royal Trinity, St John's & Elizabeth and the CLCH Pembridge Unit to provide specialist palliative care.



Current provision

The current level of provision across the 3 CCG areas include:

- inpatient beds – operating 24/7 and providing symptom control, assessment of condition and care needs
- community support from a MDT including doctors, nurses, social workers and a specialist pharmacist
- day care and home visits – offering palliative care and complementary therapies;
- 24/7 advice and guidance – a consultant led service
- bereavement services – providing emotional counselling and support to families and carers
- community nursing specialists – providing symptom management to patients and educational services to primary care teams
- Hospice@Home – emergency respite care for up to 1 week
- lymphedema Service - For patients with upper and lower limb Lymphedema
- Macmillan end of life supportive care facilitators.

Submitting evidence

To submit evidence to the Independent Chair, please complete the relevant section of the questionnaire provided, and submit your response via email to nwccgs.triborough.palliativecare@nhs.net. Further information is available at www.centrlondonccg.nhs.uk/your-services/palliative-care.

Alternatively, print and post back to us at - FREEPOST HEALTHIER NW LONDON